

VU Research Portal

Advance directives in dementia care

de Boer, M.E.

2011

document version

Publisher's PDF, also known as Version of record

[Link to publication in VU Research Portal](#)

citation for published version (APA)

de Boer, M. E. (2011). *Advance directives in dementia care: perspectives of people with Alzheimer's disease, elderly care physicians and relatives*. [PhD-Thesis - Research and graduation internal, Vrije Universiteit Amsterdam].

General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal ?

Take down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

E-mail address:

vuresearchportal.ub@vu.nl

SUMMARY

Advance directives in dementia care

**perspectives of people with Alzheimer's
disease, elderly care physicians and relatives**



SUMMARY

This thesis reports on a study on advance directives, more specifically advance directives for euthanasia (ADEs) in dementia care, and consists of two parts preceded by a general introduction and concluded with a general discussion. The first part ‘Dementia: the patient’s perspective’ describes the experiences of people with dementia with their disease and their perspectives on future care and treatment. The second part ‘Advance directives in dementia care’ deals with the experiences of elderly care physicians (ECPs) and relatives of people with dementia and advance directives for euthanasia in the practice of Dutch nursing home care.

Chapter 1, the general introduction, reports on the background and the aims of this study. The number of people with dementia is increasing and this increase is expected to continue in the future. Many people are fearful of developing Alzheimer’s disease or related dementias, and are looking for means to avoid a future life with dementia. One of the possibilities to avoid a life with dementia is to prepare a written advance directive, which may include a request for euthanasia. Since the introduction of the ‘Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2002’ – in short euthanasia law – in the Netherlands it became possible, in principle, for incompetent people, such as people with dementia, to have their advance directive for euthanasia complied with, as long as the other requirements of due care are taken into account. However, the use of advance directives, especially advance directives for euthanasia, remains a much-debated subject that raises a number of key issues. These include: 1. The experienced suffering of people with dementia and the applicability of the requirement of unbearable suffering in the euthanasia law; 2. The dilemma of discrepancies between earlier wishes and current interests of the patient with dementia; 3. The application of the requirements of due care in case of an advance directive for euthanasia of patients with advanced dementia; 4. The changing opinion on the role of advance directives as instruments for advance care planning. As the perspective of people with dementia themselves has been mostly absent in the debate on life-terminating actions in cases of dementia, the first part of this thesis focuses on the experiences of people with early-stage dementia with regard to their disease and their perspectives on the future and future care and treatment. The second part of the thesis focuses on how advance directives for euthanasia affect patient care in Dutch nursing homes. This part is based on the experiences of elderly care physicians and relatives of patients with dementia against the background of the Dutch euthanasia law.

Part I Dementia: the patient’s perspective

Chapter 2 describes the results of a literature review on what is known about living through dementia from the patient’s perspective and summarizes all that, based on this literature, can be said about the question whether dementia actually involves the suffering that is feared by the general public. The most commonly used scientific databases were searched for publications on the subjective experiences of people with dementia. Literature up to

September 2006 was included and additional relevant papers were retrieved through the reference lists of identified papers and suggestions of fellow-researchers. A total of 50 papers met the inclusion criteria.

The findings of these reviewed papers provide insight into the impact of dementia and the ways that the people affected deal with its effects by using different coping strategies. The literature on the perspective of the patient contains no solid evidence in support of the widespread assumption that dementia is necessarily a state of dreadful suffering. Although the impact of dementia and the experiences of loss resulting in multiple “negative” emotions cannot be denied, our findings also indicate that people do not undergo the disease passively and use both emotion-oriented and problem-oriented coping strategies to deal with its challenges. The experiences of living through dementia as told by the persons with dementia themselves appear to yield a more nuanced picture than the assumptions made by the general public would suggest.

Chapter 3 discusses part of the results of the qualitative exploratory survey in which interviews were conducted with 24 community-dwelling elderly people (mean age 76.3 years) with early-stage Alzheimer’s disease, covering their personal experiences with regard to their illness and the extent to which they experience their situation as one of ‘suffering’. The interviews were semi-structured and were exploratory in nature ; all were transcribed verbatim, and subjected to qualitative analysis.

An important finding is that these elderly persons were found to be very capable of sharing experiences about their disease. Their experiences appeared to be dependent on the degree of awareness of their cognitive problems, the specific consequences of the disease they experienced and the way in which they were coping with these consequences. The experiences of the participants appeared less negative than the ideas ‘healthy’ elderly often have about a life with dementia. A second important finding is that the often insidious onset and gradual progression that is distinctive of Alzheimer’s disease allows people to adapt and adjust to their changing situation. As a result, the actual experiences of the disease may deviate, in a positive sense, from the ideas of the general public and their own anticipatory beliefs. Such differences should be carefully considered in discussions on advance directives, because there is a reasonable chance that, in the end, people with dementia will not act in accordance with their earlier values and anticipatory beliefs regarding a life with dementia. From this perspective it becomes essential to communicate with people with dementia on a continuous basis. Communication with people with early-stage Alzheimer’s disease appears to be quite possible, and is essential in planning future care and treatment, especially if the aim is to adjust advance care planning to their actual wishes and needs.

Chapter 4, based on part of the results of the qualitative interviews, held with 24 community-dwelling elderly people with early-stage dementia of the Alzheimer’s type, focusses on their thoughts with regard to future care and treatment and the implications for advance care planning. All interviews were transcribed verbatim and subjected to qualitative analysis.

The interviews showed how, for people with dementia, thinking about the future is an ongoing process of balancing hopes and fears that is influenced by several internal (e.g. feelings of burdening others, attribution of the experience) and external factors (e.g.. information and treatment received). This balancing seemed to result mainly in ‘living life

one day at a time' and relying on others, rather than initiating actions with regard to looking ahead and planning for the future. These findings show that thinking about the future and engagement in advance care planning is limited among people with early-stage Alzheimer's disease on their own initiative. The fact that the possibilities for active involvement in advance care planning of people with dementia will diminish over the course of the disease due to cognitive deterioration, along with the fact that thinking about the future is not matter-of-course for these people, demands initiatives from others than the people with dementia themselves. However, taking into account the fact that people in the early stages of AD are primarily trying to cope with their condition and are not inclined to look ahead, it is essential that interventions aimed at stimulating ACP are in tune with the needs and wishes of the patient. Whether it is ethically justified, under all circumstances, to stimulate and steer people towards ACP remains a delicate question. The results show that people with early-stage AD also adapt to their changing situation, which may also change their thoughts and wishes over the course of the disease. This may lead to a situation in which discrepancies emerge between the patient's current interests and the wishes laid down in his/her earlier directive. This suggests the role of advance directives in the context of advance care planning may need to be reconsidered.

Part II Advance directives in dementia

Chapter 5 summarizes the essence of the ethical debate on advance directives in cases of dementia. This debate was shown to focus on the dilemma of how to respect the wishes and interests of an incompetent person with dementia and yet do justice to the wishes expressed in his/her advance directive. In summary, the points of view within this debate vary between two extremes. On one end of the spectrum the validity of advance directives is disputed because the person with dementia is viewed as another person [Parfit, 1984]. The reasoning is that if an advance directive can never be applied to a person who did not prepare it, and if the person with dementia is viewed as a different person from the one who once prepared the advance directive, then the directive can never be applicable to the person with dementia. Those on the other end of the spectrum hold that the preferences laid down in an advance directive represent the individual's appraisal of where his/her critical interests lie, and this should prevail over the interests of the incompetent person with dementia. In other words they argue in favour of the primacy of 'precedent autonomy' [Dworkin, 1986]. In the more nuanced approaches overriding an advance directive can be justified in cases of a good quality of life of the person with dementia based on experiential interests [Dresser, 1995] or when the person is still able to express his/her current wishes based upon their 'capacity to value' [Jaworska, 1999]. While the ethical debate focuses on how to respond to the current wishes and/or interests of a patient with dementia if these differ from the patient's wishes as described in an advance directive, the focus in actual practice seems to be different. The very limited empirical data (9 studies) about the Dutch situation, gathered through experts and a PubMed search, showed that the main factors in medical decision making in such cases are not found in the patient's perspective, but in the medical judgement of the physician and the influence of relatives of the patient. Insight into the actual experiences of people with dementia themselves regarding advance directives is lacking altogether in empirical research. Empirical research did show that, although

physicians and relatives seem to have a positive attitude towards the validity of advance directives, ADEs are seldom complied with and seem to only marginally influence the decision-making process.

Chapter 6 reports on part of a survey completed by 434 elderly care physicians who work in Dutch nursing homes. It provides insight into current practices regarding compliance with advance directives for euthanasia in cases of incompetent patients with dementia, against the background of the legal possibility to perform euthanasia in these cases offered by the euthanasia law of 2002.

Over the years 2005–2006, many elderly care physicians took care of patients with dementia and an advance directive for euthanasia. Most physicians worked in a nursing home that has a policy on euthanasia, but less than half of these physicians indicated this policy included information on euthanasia in the specific case of dementia. When information on euthanasia in dementia was included, it commonly said that advance directives for euthanasia of patients with dementia are not complied with, although they are taken into account in the form of a restricted policy of treatment (limitations on life-sustaining treatments). Advance directives for euthanasia were discussed in most cases, but actual life termination of patients with dementia took place very rarely and never in incompetent patients with dementia. This led to the conclusion that, although the enactment of the Dutch euthanasia law in theory provided a window of opportunity for euthanasia in incompetent patients with dementia and an ADE, it has not led to obvious changes in compliance with advance directives for euthanasia among this patient group in practice.

Explanations for the reticent attitudes of elderly care physicians with regard to complying with advance directives for euthanasia of incompetent patients with dementia as found in this study, include difficulty determining the ‘unbearableness’ of the suffering and choosing the right moment of carrying out the advance directive for euthanasia. However, crucial in the reticent attitudes of elderly care physicians appears to be the lack of meaningful patient–physician communication. Such communication is considered essential in cases of requests for euthanasia and these conversations cannot be captured in, or replaced by, an advance directive for euthanasia. The paradoxical nature of this situation raises questions about the feasibility of advance directives for euthanasia in advanced dementia and the enforcement of the law on this point.

Chapter 7 provides insight into how advance directives for euthanasia affect care for dementia patients in Dutch nursing homes from the perspective of both elderly care physicians and relatives of patients with dementia. Data for this chapter were derived from the survey completed by 434 elderly care physicians, 110 cases histories provided by the elderly care physicians in the survey, 11 additional interviews with physicians, and 8 interviews with relatives of deceased patients with dementia who had an advance directive for euthanasia.

Although 110 physicians described a case in which they had treated a patient with dementia who had an advance directive, none of them reported compliance with the ADE. Despite the law-based possibilities advance directives for euthanasia are not complied with in cases of patients with advanced dementia, although they do seem to have a supportive role in setting limitations on life-sustaining treatments. It was found that meaningful communication with the patient is essential for physicians to consider compliance with an advance directive for

euthanasia. Relatives also appeared to be reluctant to comply with advance directives for euthanasia. A remarkable statement was that directives were often not discussed after they were completed. Instead of euthanasia, decisions were made to forgo life-prolonging treatment. Both relatives and elderly care physicians felt supported in making these choices by the presence of the advance directive.

Chapter 8 summarizes the main results and key issues of this thesis, and presents relevant methodological considerations of the research conducted. Subsequently conclusions are drawn and recommendations are made for dementia care practice and future research.

Some aspects of the research results should be interpreted carefully. The results of the literature review about living through dementia from the patient's perspective cannot be specified to types of dementia, nor can they be generalized to all stages of dementia, as all data were collected among people in the earlier stages of the disease. However, as the interviews also focussed on people with early-stage dementia the results are relevant here. Although there might be a selection bias in the interviewed group of people with dementia (more aware of their situation and actively seeking help), the interviews do provide important results, and the implications and recommendations based on these results will also be relevant for people with early-stage dementia who are less inclined to seek help.

The results of the interviews with relatives of people with dementia and an advance directive for euthanasia should not be generalized to all relatives but they do provide relevant insight into a variety of experiences, which allows conclusions (see chapter 7) to be drawn. Interpretation of the experiences of elderly care physicians should also be approached carefully as the data were gathered indirectly through a survey and not by observation. Nonetheless, the data provided in the 110 case histories do represent actual physician behaviour in real cases. This makes it possible to 'look beyond' attitudinal aspects that may have resulted in socially desirable answers instead of answers that reflect actual behaviour.

One conclusion was that the experiences of people with early-stage Alzheimer's disease are not necessarily as negative as the widespread assumption of the general public suggests. The gradual progression of the disease allows people diagnosed with dementia to adapt and adjust to their changing situation. This in turn may result in adjustments of previous thoughts regarding a life with dementia, possibly in contradiction with a previously written advance directive. As people with early-stage Alzheimer's disease tend to live by the day and stay away from thinking about the future, help and support from others is needed in order to stimulate them to engage in advance care planning. However, the window of opportunity is limited here because possibilities for active involvement of patients with dementia in advance care planning will diminish as the disease progresses. Because of their static character, advance directives in their present form do not seem to be the most appropriate instrument in advance care planning.

Another conclusion was that despite the opportunities provided by the euthanasia law in the Netherlands to comply with advance directives for euthanasia of incompetent patients with dementia, this has not (yet) resulted in changes in Dutch nursing home practice: advance directives for euthanasia are still rarely complied with and never in patients with advanced dementia. At present their effect seems to be limited to a supportive role at best in setting limitations on life-sustaining treatments. The crucial factor for the non-compliance with advance directives for euthanasia of people with advanced dementia seems to lie in the fact

that the actual wish of the patient and the possibility to communicate about this wish are crucial for elderly care physicians to consider life-terminating actions in patients with dementia. In addition, relatives of incompetent people with Alzheimer's disease also seem to be reluctant with regard to complying with advance directives for euthanasia. Considering the essence of meaningful communication with patients about their advance directive for euthanasia, and the fact that physicians have no legal obligation to comply with these directives, euthanasia in dementia in current practice in the Netherlands seems to be reserved for patients in the early stages of the disease who are still able to actively communicate their wishes.

Based on the results and conclusions of this study it is recommended that more accurate and nuanced information about living through dementia is made available to patients, their families, professional caregivers and the general public. It is recommended to guide people with dementia in the process of planning their future by means of 'advance care planning'. This requires the development of adequate models for implementing advance care planning in dementia care. The limitations of advance directives as a potential outcome of this process need to be taken into account and the development of a practical guide with regard to the possibilities of euthanasia in dementia is recommended. Future research should focus on the development of adequate sources of information about 'living through dementia' based on the experiences of people with dementia themselves. Furthermore, the development of a practical guide on (the possibilities of) euthanasia in dementia, and the development of models of advance care planning should be given priority. Finally, longitudinal research is recommended to study the effects of advance care planning in dementia care.